The Lived Experience of Waiting for a Heart Transplant

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Abstract

In the United States, 3,782 patients are on the waitlist for a heart transplant as of November 2019. Heart transplants are often the last hope for patients with end-stage heart failure. There are multiple conditions that can lead to heart failure such as ischemic heart disease, congenital heart defects, and arrhythmias. Obesity and diabetes are both contributing factors to the increasing prevalence of heart failure. It is estimated that by the year 2030 the number of people diagnosed with heart failure will increase by 46 percent (Benjamin, et al., 2017). As a result, the need for donor hearts is expected to continue to rise. Although heart transplants have shown to be an effective treatment option for end-stage heart failure, most patients spend months waiting to receive a donor's heart. Consequently, patients often physically deteriorate and some die while waiting. Due to the uncertainty during the wait and the progressive nature of heart failure, patients face a variety of psychological, emotional, and physical problems while waiting for a heart transplant. Understanding the challenges patients face while waiting for heart transplants can improve care during the wait and improve post-transplant outcomes. This study aims to describe the current lived experience of patients waiting for heart transplants in the hospital and home settings.

Introduction

Around 5.7 million adults are currently diagnosed with heart failure in the United States (2019). Heart failure is caused by impairment of the myocardium, which causes ventricular ability to fill or eject blood to decrease (Inamdar & Inamdar, 2016). There are multiple conditions that can lead to heart failure, including ischemic heart disease, congenital heart defects and arrhythmias (Inamdar & Inamdar, 2016). Due to the chronic and progressive nature of the disease, the treatment options range from lifestyle modification and medications to ventricular assistive devices and heart transplantation (Inamdar & Inamdar, 2016). Heart transplantation operations are defined as the replacement of a recipient's heart with a deceased donor (Kim, Youn, & Kobashigawa, 2018). Heart transplants are indicated for patients with end-stage heart failure, refractory angina and ventricular arrhythmias who remain symptomatic after receiving optimal medical treatment (Kim, Youn, & Kobashigawa, 2018). The criteria used for qualifying patients to receive transplants are focused on subjective data, resting hemodynamic data and New York Heart Association classification (Alraies & Eckman, 2014). There are a variety of contraindications for receiving a heart transplant (Kim, Youn, & Kobashigawa, 2018). Examples of potential contraindications include irreversible liver, lung or respiratory failure, advanced age, severe obesity, psychological instability, lack of social support or limited resources (Kim, Youn, & Kobashigawa, 2018). These are not absolute contraindications and exceptions can be made depending on specific circumstances.

Although qualifying to receive a heart transplant can be challenging, transplants have been shown to be an effective treatment option, with a 1-year post-transplant survival around 90% (Colvin, et al., 2019). Furthermore, they have been shown to have improvements in quality of life (McCartney, Patel, & Rio, 2017). Unfortunately, the current need for donor hearts exceeds

the demand. Additionally, the process of evaluating donors is also a grueling task. Thorough past medical histories, physical examinations, and cause of deaths are needed (Kim, Youn, & Kobashigawa, 2018). Examples of characteristics of favorable donors include being under the age of 55, absence of significant structural or functional abnormality, donor recipient body size within 20-30% of height and weight, and no history of severe infections (Kim, Youn, & Kobashigawa, 2018). As a result. fewer than 50% of potential donor organs in the United States are used (Kobashigawa, et al., 2017).

In the United States, 3,782 patients are on the waitlist for a heart transplant as of November 7, 2019 (Health Resources and Services Administration), and the average wait time to receive a heart transplant is 6 months (Colvin, et al., 2019). Depending on the severity and management required, patients are able to wait both in the hospital and at home. Regardless of the location, many patients will physically decline. As a result, patients both die on the waitlist or are removed after becoming unqualified due to worsening conditions (Goldstein, et al., 2016).

Left ventricular assist devices (LVAD) were created as a final means to temporarily support cardiac function and relieve symptoms for patients waiting on heart transplants (Capriotti & Micari, 2019). LVADs require open-heart surgery and are indicated for patients who are refractory to medical management, or refractory to external mechanical support devices (Pruijsten et al., 2012; Sikic, 2011). According to the International Society for Heart and Lung Transplantation, around 47% of international adult heart transplant recipients had a ventricular assistive device prior to transplantation from 2010-2018 (2019). LVAD devices are used to assist the ventricle in providing adequate blood flow throughout the body (Capriotti & Micari, 2019), Research has shown that patients who receive LVADs have had a reduced death rate of 48% compared to patients depending solely on medical therapy (Sajgalik et al. 2016). Furthermore,

they have been shown to enhance mobility and improve quality of life (Prinzing, et al., 2016). As a result of the effectiveness of LVADs, they have become indicated for destination therapy and bridge to recovery in the last decade (Prinzing, et al., 2016). Destination therapy is used to prolong and improve the quality of life of patients who do not meet the criteria to receive a transplant (Prinzing, et al., 2016). Bridge to recovery therapy is used to temporarily support the native heart to facilitate function recovery (Davis, Kaan, Cheung, & Kang). Although LVADs allow patients to survive longer on the waitlist, some patients still die while waiting for a heart transplant (Goldstein, et al., 2016).

The process of waiting for a heart transplant is unpredictable and challenging. During the waiting process, patients have a wide range of feelings and emotions. Psychiatric morbidity rates are around 50% for people waiting for heart transplants, mainly anxiety or depression (Haugh & Salyer, 2007). Understanding the lived experience of patients waiting for heart transplants is the first step in facilitating effective, and compassionate care during the wait. Furthermore, research has shown that the psychological status of a patient before a heart transplant can affect post-transplant surgery success (Ye, et al., 2013). The purpose of this literature review is to explore the lived experience of patients waiting for heart transplants in the inpatient and outpatient settings.

Methods

Four web databases, CINHAL, PubMed, PsycINFO, and Scopus, were used to search for related articles on the experience of waiting for a heart transplant. Due to the limited number of recent articles studying the lived experience of patients waiting for transplants, the range of dates of the articles included were January 2004 to December 2019. The search terms used in this project were identified over the course of multiple meetings with a university librarian and

liaison to nursing. Search terms included: heart AND (transplant OR transplants OR transplantation OR transplantations) AND (wait OR waiting OR waitlist OR waitlists) AND (qualitative or lived experience or "focus groups" or interviews). The inclusion criteria for this review included: 1.) a focus on the lived experience of individuals waiting on heart transplants and 2.) empirical studies. Exclusion criteria included a focus on: 1.) organ transplant need other than heart and 2.) population under the age of 15 years old. Fifteen years old and older was included in the study because they are typically of similar size and weight to adults. After the search was completed, the final step was reviewing the full text to identify themes related to the experience of patients waiting on heart transplants.

Results

The search terms resulted in 38 articles. After removing 2 duplicates, a total of 36 articles were identified (Figure 1). After reviewing the remaining articles' abstracts and conducting full-text reviews, a total of 10 articles were included in this study. 26 studies were excluded for being quantitative only, a focus on the transplantation of organs other than the heart, a focus on a pediatric population, or a focus on family members or spouses. Of the studies selected to be included in this research, five studies used qualitative analysis study, and one was a secondary qualitative analysis. Seven of the studies were international, two from the United Kingdom, one from Canada, one from China, one from Brazil one from Italy, one from Poland. The remaining three were conducted in the United States. Five of the studies were conducted in the hospital setting, four of the studies were conducted in the home setting, and one study had participants in both the home and inpatient setting.

Four of the studies included waitlisted heart transplant patients, four studies included waitlisted heart transplant patients with LVAD’s, one study included waitlisted heart transplant

patients and their spouses, and one study included waitlisted heart transplant patients and their families. Six of the studies interviewed pre-transplant patients, three studies interviewed both pre and post-transplant patients, one study interviewed post-transplant patients. Based on the studies that provided specific information regarding the genders of the participants, 131 out of the 158 participants were males. The age of each participant was not included in all the studies; therefore, an accurate mean age could not be calculated. However, the age range of all the studies was 15-74 years old. All the participants were at least 18 years old except one which included a 15-year-old (Sadala & Stolf, 2007). Excluding this study would result in losing valuable information from the other 25 participants because it was not possible to separate the data (Table 1).

Five distinct themes emerged from the ten studies: 1.) Life limitations (n=8); 2.) Contemplation of donor death (n=3); 3.) Uncertainty of the future (n=9); 4.) Spirituality (n=4); and 5.) Support from others (n=3) (Table 1.1).

Life Limitations

Eight studies provided accounts describing different limitations experienced while waiting for a heart transplant. Sadala & Stolf (2007) conducted interviews with patients waiting to receive heart transplants in the home setting in Brazil. The participants were asked a single question “What does the experience of being a heart transplanted mean? (Sadala & Stolf, 2007, p. 217).” Participants discussed the discomfort caused by not being able to live their normal life. The participants experienced limitations related to their physical decline. Even the most essential functions, such as breathing, eating, or walking became impossible (Sadala & Stolf, 2007). In 2016, Krimminger explored the lived experience of patients implanted with LVAD’s waiting for heart transplants in the home setting in the United States. In the qualitative study, Krimminger

(2016) performed interviews using Van Manen's phenological model to code themes. In the study, medical equipment and devices appeared to cause further limitations. The participants noted that being attached to wires-imposed reduced the activities they could perform. Further, many of the participants found that being hooked up to wires and alarms made them feel dependent on machines (Krimminger, 2016).

In the United Kingdom, Hallas, et al., (2009) conducted a cross-sectional study, qualitative study to explore the psychological adjustments of patients after receiving VAD's compared to those who had transplants, or the device explanted. The researchers conducted one on one interviews using topics from chronic illness literature related to psychological adjustments to guide the interviews. After, data was analyzed based on the grounded theory approach (Hallas, et al., 2009). Having sense of control was important for all participants in the study. This importance of control appeared to stem from having experienced limitations caused by their illness. The participants noted having to build new routines, due to the limitations caused by their illness, strict medical regimens, and regular hospital visits (Hallas, et al., 2009). One of the participants from the study stated, "I can't move around as I used to, I can't run, I can sort of do stairs now, but I need help…I need someone with me all the time" (Hallas, et al., 2009, p. 36).

Lee (2004) conducted a qualitative study assessing the lived experience of heart failure patients waiting on a transplant in Hong Kong. Based on the ideas of Husserl, the study used interviews on 6 male participants in the hospital and home setting (Lee, 2004). Participants experienced multiple physical limitations during the wait. One participant from the study stated, "When doing some physical work, after only 15 seconds, I felt short of breath" (Lee, 2004, p. 65). Another common problem was sleep disruption caused by cardiac dysfunction and hypoxemia (Lee, 2004). Furthermore, due to the limitations, many of the participants were

unable to continue their careers. As a result, patients experienced feelings of worthlessness (Lee, 2004).

Pool et al., (2016) conducted a secondary analysis study in Canada examining the grief and loss heart failure patients experienced while waiting for a transplant. The researchers analyzed audiovisual interview data from previously conducted interviews on 50 participants listed for heart transplant at home. From the interviews, Pool et al., (2016) coded transcripts and generated themes and analytic categories. The themes of Loss and Anticipatory grief emerged from the study (Pool et al., 2016). Participants experienced feelings of loss of their prior life, future life, and autonomy. Both the loss of prior life and autonomy were related to physical limitations.

In the United Kingdom, Standing, et al. (2017) explore the lived experience of LVAD patients wanting on heart transplants in the hospital. The study used an interpretive phenomenological approach based on Heidegger interviews. The participants noted that they lost the ability to perform many basic daily life tasks (Standing, et al.). For example, limiting their ability to play with their children or attend sporting events. Participants had similar experiences, in mixed-method study conducted in Italy by Modica, et al. (2014) using both in person interviews and questionnaires to explore the quality of life, anxiety and depression caused by LVAD implementation while waiting for heart transplants. Participants noted that managing their LVAD decreased their sense of autonomy.

Haugh & Salyer (2007) conducted a qualitative study in the United States focusing on exploring the perceptions that patients and their family members had on the effectiveness of the interventions used during their wait for a heart transplant. The study used videotaped focused group interviewing technique to conduct the interview (Haugh & Salyer, 2007). In the study,

participants identified the importance of participating in activities that made them feel "normal". For example, playing with their pets, or eating certain foods (Haugh & Salyer, 2007). These activities that they could previously do were all disrupted by their physical limitations or dietary restrictions.

Contemplation of Donor Death

Three studies provided accounts that indicated patients waiting for heart transplants contemplated over the death of their potential donor (Table 2). Contemplation of donor death can be defined as distress and/or sadness related to the thought of waiting for the death of a potential donor (Pool et al., 2016). The process of waiting for someone else to die in order to take their heart presented a moral dilemma for many participants. In the study conducted by Hallas et al., (2009), participants experienced emotional distress caused by waiting for the death of a donor. Seven out of the ten participants in the study conducted by Krimminger, (2016) found that waiting for the death of a donor created uncertainty and discomfort. One participant shared, "…I don't want anyone else to die but that is the only way I can live without this machine" (Krimminger, 2016, p.132). Another participant shared that he was "excited, but sad (long pause and tearing up) because someone, somebody has to die for me to live…" (Krimminger 2016, p.132) Similarly, in the study done by Pool et al., (2016) participants waiting for heart transplants experienced anticipatory grief and guilt caused by contemplating over the death of their potential donor. A participant from the Pool et al. (2016) study stated, "…somebody has to die for me to have a heart. That's the only…only thing I can think of right now" (p. 195).

Uncertainty of future

The idea of uncertainty in relation to illness has been extensively studied (Etkind, et al., 2017). The finding of participants experiencing uncertainty during the process of waiting for a

heart transplant supports Merle Mishel's theory of uncertainty in illness. Mishel's uncertainty in illness list four factors related to uncertainty: complexity, unpredictability, lack of information and ambiguity (Etkind, et al., 2017). Nine of the studies addressed having uncertainty of future as a theme. Participants from multiple studies experienced discomfort in not knowing when the heart will become available, or if they will survive long enough to receive the heart transplant, or survive the surgery (Haugh & Salyer, 2007; Modica, et al., 2014). Participants from the Haugh & Salyer (2017) study found that the process of having to wait for a heart led to participants having uncertainty over their future. A participant from the study conducted by Pool et al. (2016) stated "… the waiting for the transplant is something entirely different to me, and it's the hardest thing because you're shadow-boxing. You're fighting something you can't… you don't know when that calls going to come…" (p. 195).

Feelings of uncertainty appeared to be related to a variety of factors. Participants from the study conducted by Lee (2004) experienced feelings of uncertainty due to not knowing when a heart would become available, if they will live long enough to receive the heart, or if they will make it through the surgery. Additionally, Krimminger (2016) and Hallas, et al. (2009) identified that having to depend on a machine also played a role in the participants uncertainty. Not only did the uncertainty cause stress and anxiety, Sadala and Stolf (2007) identified that the uncertainty caused participants to like their lives are suspended and frozen in time. In a mixed method study conducted in Poland, Sauer, et al. (2007) preformed both structured interviews and used anxiety and depression questionnaires to assess the lived experience of two male patients waiting for heart transplant in the hospital. The patients in this study both acknowledged the unpredictability of their situations but maintained a high level of perceived control because of their knowledge related to their medical care (Sauer, et al., 2007).

Spirituality

Four of the studies described spirituality as a central experience in the process of waiting for a heart transplant (Haugh & Salyer, 2007; Lee, 2004; Nowicka-Sauer, et al., 2007; Sadala & Stolf, 2007). In a study conducted by Sadala & Stolf (2007), participants recounted that they believed spirituality had an impact on their outcomes. One participant stated, "God allowed me to continue living, put me in the hands of Dr E for transplantation. My family, the church I go to, everyone started praying for me" (Sadala & Stolf, 2008, p. 222). Depending on the location of the study, the spirituality beliefs varied. In Hong Kong, China, Lee (2004) identified believing in external forces as theme amongst patients waiting for heart transplants. Many of the participants believed in Yuan, which involves fate and believing in supernatural powers (Lee, 2004). When individuals were having a difficult time enduring the wait, many of them began believing in spiritual beings. Individuals began to believe that some sort of external force controlled the world; therefore, directly impacted their outcomes (Lee, 2004).

Haugh & Salyer (2007) identified that spirituality, humor, and support all played a role in facilitating coping. When a participant was asked what helped her decide to have a heart transplant she responded, "…I'm going to pray to God and let him tell me what to do… Faith gets you all the way through (Haugh & Salyer, 2007, p. 324)." Similarly, a participant in the study conducted by Nowicka-Sauer, et al. (2017) stated, "…we believe that there is hope and that God will help us…" (p. 698). Nowicka-Sauer, et. al (2017) concluded that the patients were aware that part their future was dependent on faith, destiny, or God.

Support from Others

The findings of three studies indicated that support from others while waiting for a heart transplant was helpful in coping. In the study conducted by Haugh & Salyer (2009), peer-support

was identified as being one of the most important coping mechanisms used by the participants. Three of the patients that were hospitalized at the same time while waiting for a transplant. One of the participants stated, “I think the toughest time I had was when Bob got his heart… I went in and spent the rest of the night with him till he went down for his surgery (Haugh & Salyer, 2009, p. 325) …” Participants in the studies done by Hallas, et al. (2009) and Modica, et al. (2014) also found social support to be a significant positive coping factor. In the study conducted by Modica, et al. (2014), participants believed being able to share the experiences with other people that have been through similar challenges would be beneficial. In addition to peer-support, support from health care professionals appeared to make a positive difference during the wait for some of the participants in the study conducted by Haugh and Salyer (2009). One of the participants stated, “To me the nurses were like sisters... They really are your lifeline in this hospital” (Haugh and Salyer, 2009, p. 324). Additionally, Haugh and Salyer (2009) identified that participants believed that the way health care professionals were sharing information and providing education was important.

Discussion

This systematic review of literature focused on evaluating the lived experience of patients waiting for heart transplants by compiling and reviewing the current bodies of work portraying the wait. The amount of available literature addressing the process of waiting for heart transplantation is sparse. Ten studies were reviewed in this study, all of which shared the common goal of developing a better understanding of the experience’s participants have while waiting for a heart transplant. The studies included in this review came from multiple continents, including first world, developing and third world countries. As a result, different health care

systems and cultures can impact the experience that patients have while waiting for a heart transplant.

In the United States, it is estimated that women make up around 25% of patients waitlisted for heart transplants (Hsich, et al., 2017). However, across the studies, males made up most participants sampled. In the nine studies that included gender, around 83% (131 out of the 158) participants were males. The studies conducted by Lee (2004) and Nowicka-Sauer, et al. (2017) included only male participants. Lee (2004) stated that only males were interviewed because the number of females on the waitlist was too small and all of them rejected being interviewed. Since the studies reviewed had an overwhelming male majority, using the results found from the articles to guide care for female patients may not be feasible. Female patients may have unique concerns compared to male patients because of the different roles they play in the societies in which they live.

Many of the studies were conducted on both hospitalized and at-home patients. Both settings can present different challenges. Patients in the at-home setting may experience a great sense of control over their lives. Whereas in the hospital setting patients are typically hooked up to more monitors, thus further limiting their independence. The sample sizes of the studies ranged from 2 to 50 participants, with half of the studies having 11 or fewer participants. The study conducted by Nowicka-Sauer, et al. (2017) included only two participants, both of whom were males aged 60 and 61. The lack of diversity within the literature and relatively small sample sizes may be an indication that these studies are not representing the waitlisted population. However, regardless of the sample size, many of the studies ended up with similar themes associated with the wait.

The qualitative accounts shared in this literature review provide critical insight into the lived experience of waiting for a heart transplant. The five-overarching themes identified in this review appeared to be related to two different experiences of the wait. Three of the themes appeared to be related to *the process of waiting* for a heart transplant: 1.) Life limitations (n= 8); 2.); Contemplation of donor death (n=3); 3.) Uncertainty of future (n=9). The other two identified themes were related to *coping while waiting* for a heart transplant: 1.) Spirituality (n=4) and 2.) Support from Others (n=3). The themes developed related to the process of waiting for a heart transplant are related to the challenge's participants face during the wait. Understanding these challenges can help further direct support. The themes related to coping are the strategies that participants have found to be effective during the process of waiting. Thus, these coping mechanisms could potentially benefit future waitlisted heart transplant patients.

Conclusion

The experience of waiting for a heart transplant is one of the most challenging situations a person can face, generating an abundance of stress and uncertainty. The themes identified in this study show that patients struggle both physically and psychologically. These themes help provide a better understanding of the emotions and challenges faced by the patient during the wait. The themes derived from the studies can be used to help nurses provide holistic care to patients waiting for heart transplants.

Nurses should assess the spiritual beliefs help by patients waiting for heart transplants. Nurses can help patients cope by recommending and facilitating the patients to speak with chaplains, attend hospital or online church services. Further, nurses should facilitate peer-to-peer support by connecting patients waiting for heart transplants in the hospital setting, via online or in-person support groups. Developing these connections can provide individuals with the

opportunity to share emotions, experiences, and receive advice. To help combat limitations, nurses can help patients identify ways to adjust previously performed activities to make them more realistic. For example, nurses can recommend participants spacing activities out throughout the day in order to provide adequate time for rest. Providing patient education on device management, medication, the pathophysiology of their disorder, and what to expect during the wait can help combat the uncertainty patients experience. Educating patients can also further develop a great sense of control amongst participants. Another important consideration for nurses to consider is the financial impact that the limitations can have caused by no longer being able to work. Nurses can assess the financial impact and facilitate the communication with social worker and case managers.

Future studies with an emphasis on the lived experience of patients waiting for heart transplants provide vital information needed to both better understand and care for patients during the wait. Sample diversity and size should be a consideration when evaluating the results of these studies and obtaining a larger and more diverse sample size should direct future research. Future research needs to be aimed at identifying the challenges, and methods to support people during the wait.

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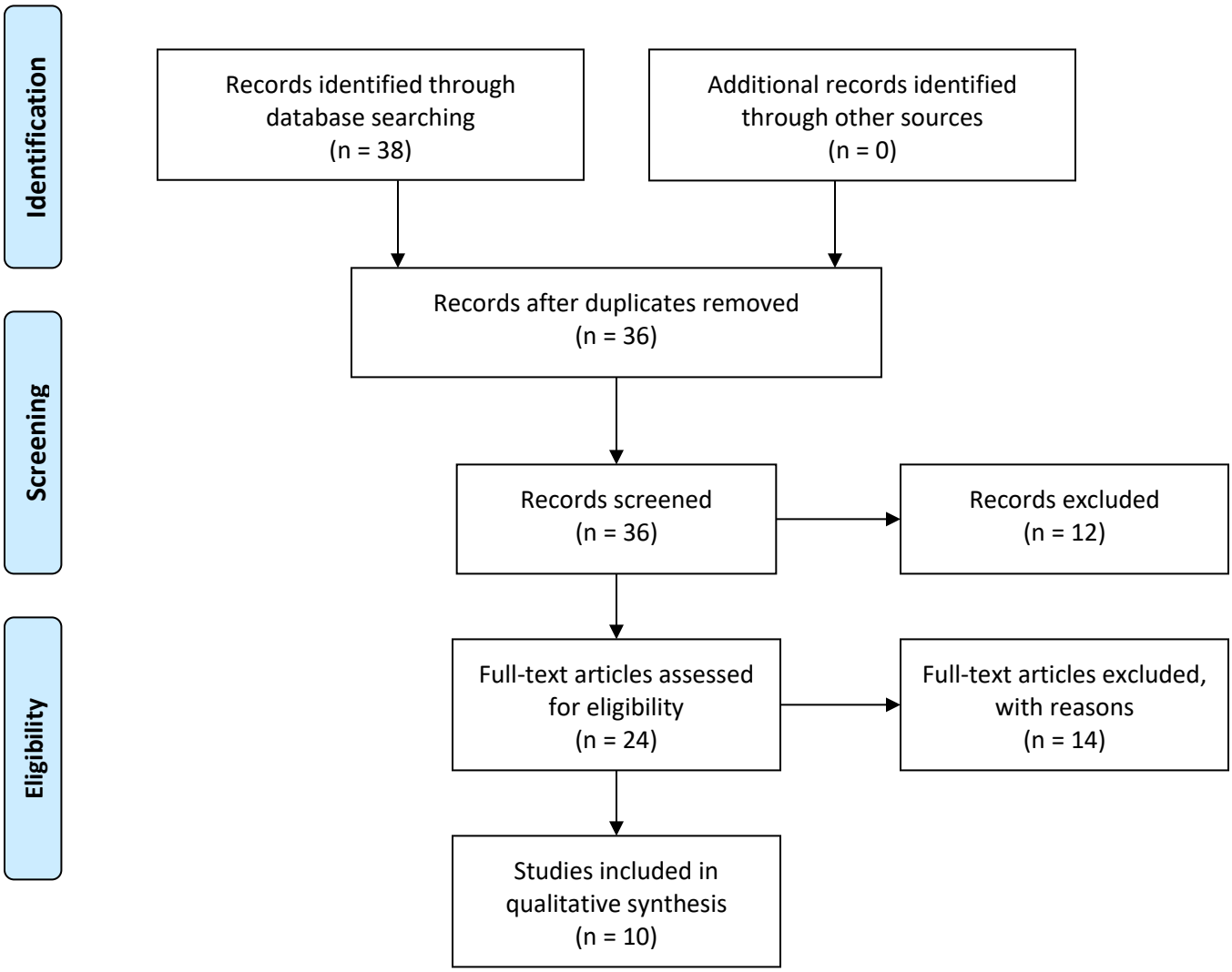
Figure 1: *PRISMA diagram (Preferred Reporting Items for Systematic Review and Meta-analysis Diagram)*



Appendix

Table 1: Summary of Articles

Author (Year)	Sample/Setting	Age/gender	Purpose	Study Design	Methods	Summary of Results
Araujo Sadala & Groppo Stolf (2007) Brazil	26 participants who were heart transplant recipients. Home setting.	Age range from 15-71. Genders were not specified.	Gain an understanding of heart transplant patients experience	Qualitative, Phenomenological approach	A phenomenological approach was used to interview participants. Participants were asked a single question: "What does the experience of being heart transplanted mean?" (Merleau Ponty Methodology). Interviews lasted between 25 and 70 minutes. Interviews were transcribed and analyzed.	Three themes emerged: 1. The time lived by the heart recipient 2. Donors, family and caregivers 3. Reflections on the experience lived. The symptoms of the final stages of heart failure had a plethora of effects on their lives. Discomfort was felt from no longer being able to perform essential functions. While waiting for a heart transplant, participants have their life suspended, they are just waiting for an uncertain result of death or life.
Burker, et al (2006) United States	22 Participants and their spouses undergoing evaluation for heart transplant. Hospital setting.	21 Male participants, 1 female participants. Heart transplant candidate age range 39-61 (mean 47.6)	Explore if a relationship exists between heart transplant patient's depression and spousal coping strategies.	Descriptive exploratory pilot study	Used structure interview guide for the Hamilton Depression Scale to interview participants. COPE inventory and the Center for Epidemiological Studies Depression Scale were completed by the spouses.	Planning was frequently reported as a beneficial coping style. Behavioral disengagement and denial were not as useful or used as often. Spousal depression showed no significant correlation with heart transplant patient depression. However, spousal coping strategies of behavioral disengagement had a significant associated with transplant patient's depression. Spouses were more depressed than transplant patients.

						Identification during the pre-transplant evaluation of maladaptive coping strategies used by spouses could help with early interventions.
Dawn Marie Krimminger (2016) United States	10 Participants waiting for heart transplant with LVAD in the home setting	Participants between 30 and 60 years old. 10 male and 1 female.	Explore the lived experience of patients implanted with LVAD's who are waiting for a heart transplant.	Qualitative, phenomenological study	One on one interviews were conducted and analyzed to find themes. Van Manen's phenological method was used to code themes. Data was gathered through interviews and observations.	Six Themes identified: 1. Batteries and wires 2. Do it 3. Hooked up and the alarms 4. I get frustrated at times 5. I need a heart 6. Part of me were identified Many participants noted managing wires and batteries as being a challenge that took time to get used to. Advice to other potential VAD recipients was "just do it". Participants seen the device as an opportunity to live longer and improve their QOL. Being hooked up to the alarms made participants feel dependent on a machine to live. Alarms produced anxiety. Every participant had frustrations while living with an LVAD. They noted having to always think before they could perform activities. Participants feared not knowing when their health would deteriorate, having to depend on a machine, and having to wait for a donor created a lot of uncertainty. Participants shared feelings about having to wait for someone else to

						die. Participants viewed LVADs as a part of their body. Participants expressed that their quality of life improved after receiving an LVAD.
Hallas, et al. (2009) United Kingdom	11 participants, 4 living with VAD in situ, 4 maintained on anti-heart failure, 3 received a heart transplant Hospital setting.	8 men and 3 women. Age range 18 to 60 years old, mean age 42.9.	Explore the psychological adjustment of patients after receiving VAD compared to those who had transplant or had the device explanted.	Qualitative cross-sectional study.	In person interviews were 1 to 2 hours long and recorded. Topics identified in chronic illness literature related to psychological adjustment guided the interviews. Data was analyzed based on the grounded theory approach. 2 independent raters analyzed the data collected by the interviews to assess stability and interrater reliability.	Control was the core category related to psychological adjustment 6 conceptual categories were associated: 1. Normality 2. Uncertainty 3. Emotional state 4. Identity of illness/VAD 5. Impact of VAD 6. Independence All the participants identified uncertainty, emotional state, and normality and 3 categories associated with perceived control. Independence correlated to a greater sense of control and more positive adjustment after VAD explant. All patients focused on normalization through cognitive comparison with others or their pre-illness lives. Transplant patients had more long-term health concerns, while VAD and explant patients had more short-term uncertainties. The participants emotional state largely influenced their sense of control. VAD explant patients focused on identity of the heart failure and impact of the VAD.

						Transplant patients focused on maintaining independence, which was related to their sense of control. Participants noted concerns about VADs effecting their physical appearance.
Haugh & Salyer (2007) United States	11 participants. 4 post-transplants, 4 pre-transplants, 3 family members. Home setting.	Average age 48.4 years old. 5 out of the 8 patient participants were male.	Explore the perceptions of patients waiting on heart transplants and their family members on the effectiveness of the interventions used during their wait.	Qualitative	Videotaped focused group interviewing technique was used to determine the perceptions of the participants and identify themes.	Themes that emerged: 1. Tolerating uncertainty 2. Sharing information 3. Sensitivity to family needs while hospitalized. 4. Maintain respect and dignity 5. Doing extra little things 6. Facilitating coping The central theme identified was tolerating uncertainty. Participants noted that they had to learn to tolerate uncertainty, and no one could tell them when they would receive a heart. Participants noted that the uncertainty, increasing severity of their symptoms and medical intensive medical management were all stressful. Participants noted feeling a loss of control over their condition. Subthemes were developed related to interventions that the participants thought were helpful. Participants were not concerned about how VADs effected their physical appearance.

Lee (2004) China	6 heart transplant candidates. Either at home or in the hospital (did not specify amount in each)	All Male.	To explore the experience of male Chinese heart failure patients waiting on transplant.	Qualitative, phenomenological approach	Used phenomenological approach based on ideas of Husserl. Interviews with patients in hospital or at home.	Four main themes developed from interviewed data: 1. Enduring the wait 2. Preserving self while waiting 3. Making sense of wait 4. Believing in external forces Waiting caused a lot of uncertainty and participants felt like their lives were suspended. Patients expected that they would encounter problems during the waiting period. Patients relied on both internal and external forces to endure the wait. Patients complained of feeling physical discomfort. Participants reported living day by day and not thinking about problems. They believed it was necessary to at least minimally continue their home activities. The participants accepted their situation and tried to prepare for the long waiting period.
Modica, et al. (2014) Italy	28 participants with LVAD implanted. 22 patients were bridge to transplant and 6 were destination therapy.	Aged 18 or older (mean 54 years old). 27 male, 1 female.	Explore the quality of life and psychological symptoms after LVAD implantation.	Mixed method	Participants underwent at least 3 in person psychological interviews lasting around 1 hour during their second month after LVAD implantation. Unstructured and open-	Identified 6 main concepts influencing VAD acceptance: 1. The device characteristics 2. The experience of the disease during the wait time for heart transplant. 3. The nature of the assisted organ

	Hospital setting.				ended questions. QOL was assessed using the Short Form 36 of the Medical Outcomes Study and the Minnesota Living with Heart Failure Questionnaire. The Hospital Anxiety and Depression Scale and the Coping Orientation for Problem Experiences were used to assess psychological characteristics. Statistical analysis was preformed to show the correlations between HADS scores and COPE pre and post-transplant.	4. The quality of patient-doctor communication 5. The possibility of sharing the experience 6. The psychological characteristics of the recipient. LVAD recipients improved quality of life; however, their emotional distress was still high. Bridge to transplant patients seemed to adapt worse than destination therapy patients. However, the participants perceptions of the LVAD as a passage to an improved life provided by heart transplant can help with acceptance.
Nowicka-Sauer, et al. (2007) Poland	2 participants who were on heart transplant waitlist. Hospital setting	Male patients. 60 and 61 years old.	Explore individual patient experiences while waiting for heart transplant.	Mixed method	Performed structured interviews, the Pictorial Representation of Illness and Self Measure, Hospital Anxiety and Depression Scale, the Illness Cognition Questionnaire, and the Illness perception Questionnaire-Revised.	Themes: 1. Hope 2. Illness Coherence 3. Perceived control Participants viewed significant others and hope as important and valued realistic cognitive pictures of the disease. Patients showed a sense of control and understanding of the illness, which was perceived to be related to their compliance, knowledge and medical care. However, the patients also

						understood that their future depended on fate, destiny or god. Hope, illness coherence, and perceived control relate to a lower level of depression and anxiety.
Pool et al. (2016) Canada	50 Participants, 23 participants listed for transplant, 27 medically stable heart transplant recipients. Home setting.	Mean age 51.5+/- 9 years. 70% Male.	To examine grief and loss heart failure patients experience while waiting for a transplant or after receiving a heart.	Secondary qualitative analysis	Analysis of audiovisual interview data previously collected. Coded transcripts and generated themes and analytic categories. Noted disjunction between answers and expressions. Merleau-Ponty methodology incorporated. NVIO8 qualitative software coded text and body language, volume and tone.	Two themes emerged Pre-Transplant: 1. Loss 2. Anticipatory grief Participants experienced feelings of loss of their prior life, future life (uncertainty while waiting) and autonomy. Participants waiting for heart transplants experienced anticipatory grief in anticipation of their own possible death and the death of their potential donor.
Standing, et al. (2017) United Kingdom	20 VAD participants awaiting heart transplant and 11 partners. Hospital setting.	Male 17, female 3. Age range 21-70 years old.	Explore the lived experience of VAD recipients.	Qualitative, interpretive phenomenology.	Study used an interpretive phenomenological approach based on Heidegger. Interviews lasted between 39 and 105 minutes.	Themes developed: 1. Receipt of the VAD creates liminal identities. 2. Temporal disruption of the VAD. 3. The VAD as a liminal object. 4. Projections to the future (uncertainty) The majority of VAD recipients viewed their life as being in a temporary state, focusing on the future life without the VAD. VAD is

						perceived as relief, whereas transplantation is perceived as the cure. The main theme developed was that patients living with VADs as a bridge to transplant lived in a state of persistent liminality. Subthemes included loss of identity, temporal disruptions, sense of time changes from authentic to inauthentic, projections toward the future.

Table 1.1
The Process of Waiting for a Heart Transplant: Emerging from thematic analysis from included studies (*n* = 10) and corresponding descriptor quotes

Themes	**Exemplar**
Limitations	"…constantly being told, don't do this, don't do that, you can't do this, you can't do that (Hallas, Banner & Wray, 2009) …"
Contemplation of donor death	"…the only part that I find a little bit unnerving is that someone has to die [choked up:] for me to get a heart. So, uh, my good fortune depends on someone else's bad fortune (Poole, 2016) …"
Uncertainty of future.	"My life's in limbo, the uncertainty. I'd like to know about when it might happen. They say within 5 years. I don't think I'm going to last that long the way the last year's gone (Haugh & Salyer, 2007)."
Spirituality	"God allowed me to continue living, put me in the hands of Dr. E for transplantation (Sadala & Stolf, 2008)."
Support from others	"To me the nurses were like sisters to me... They really are your lifeline in this hospital."